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Autism = death

The social and medical impact of a catastrophic medical model of autistic spectrum disorders

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This discussion interrogates the continuing impact of the pervasive and persistent usage of debilitating metaphors perpetuating 'historical' superstitions, myths and beliefs surrounding disability. This article examines the real-life consequences of the power exercised through the deployment of derogatory metaphors and their very real effects on care and treatment decisions. The article illuminates how diagnostic categories and their associative metaphors work to situate boundaries of normality with pathologising difference. It concludes by demonstrating the catastrophic effect of the metaphoric dehumanisation of autistics that has recently culminated in murder being euphemistically referred to and condoned as 'mercy killing'.

A diagnosis of autism can be like a living death, for a child may look normal but exist in a state of limbo.

These words were not written by Bruno Bettelheim in the 1950s. They are from a 1999 article by a respected psychologist, Dr Bryna Siegel, which carries the intriguing title 'Dispelling myths about autism'.

There are so many myths about autism that a single article could hardly do the topic justice. Unfortunately, Siegel's article perpetuates one particularly resilient myth: that people who carry the label of an autistic spectrum disorder are something other than fully human and fully alive. In this discussion, I will explore the roots, expression, and effects of this myth.

According to Colin Barnes, "disability" refers to a complex system of social constraints imposed on disabled people by a highly discriminatory society', constraints based on 'superstition, myths, and beliefs from earlier less enlightened times. [These ideas] are inherent to our culture and persist partly because they are constantly reproduced through the communications media' (Barnes, 1992: 5). Among the 'superstitions, myths and beliefs' that have contributed to the formation of modern discourses about autism are the idea of the unclean or possessed body, as expressed in biblical and other texts; the myth of the changeling, which was common to many European cultures; and superstitions attached to monstrosity, particularly as regards the supposedly definitional human charac-

teristic of oral speech, and the anxiety our culture attaches to its absence.

I would add to this list the concept of the 'normal' or 'ideal' human being, a construction that was first put forward in Greek times with the advent of structured classification systems, and codified ever more tightly since the Enlightenment. The normal or ideal is necessary as a standard against which (for example) uncleanness, impairment, and degrees of non-humanness can be measured. Indeed, it is only through the identification and rejection of the abnormal and less than ideal that these concepts can be constructed at all.

These ideas have been part of human spiritual and cultural beliefs throughout recorded history. Indeed, Barnes is rather optimistic in attributing them to 'earlier less enlightened times' (Barnes, 1992: 5). The core narratives of medicine and its corollary discipline, psychology, have come to embrace many old myths, including these. The construction of autism as a disability is only one lens through which these myths can be observed in action today.

The language of autism and the narratives in which it is used function to construct distorted representations of autism and of people with the characteristics we call autism. This is significant, because it is through narratives, representations and discourses that cultures construct and transmit meanings. As Stuart Hall writes, 'meanings also regulate and organize our conduct and practices – they help to set the rules, norms and conventions by which social life is ordered and governed. They are also, therefore, what those who wish to govern and regulate the conduct and ideas of others seek to structure and shape' (Hall, 1997: 4). Although the distortions inherent in current discourses of autism are often not innately malicious – most are simply expressions of incomplete knowledge – one function of these distortions is the exercise of power. They convey the power to include or exclude, to ignore or treat, and even to control or harm, first by positioning autism as a medical condition in need of a cure and, second by rendering its 'sufferers' less than fully human.

Autism has been constructed as a medical condition defined by what Lorna Wing has termed a 'triad of impairments' (Wing and Gould, 1979: p?) affecting social and emotional development, behaviour, and flexibility of thought. No one who has worked with autistic people would deny that some individuals designated as having ASDs do experience impairments, although the extent and cause of these is often unclear. An inability to communicate verbally, for example, is not an impairment if the person can use a robust alternative strategy, such as sign language or an assistive communication device. Lack of flexibility can be accommodated in stable environments.

However, the impairments connected to autism trouble some very basic ideas about what it is to be human. What, after all, divides humans from chimpan-

zees? Both use tools, live in family groups, and communicate in some way with the members of those groups. The difference in our DNA is tiny; we are prey to many of the same illnesses. Humans, however, speak – or so say linguists such as Noam Chomsky, who claim that the capacity for verbal speech is hard-wired into our brains (Chomsky, 1957). Humans who do not or cannot speak challenge this definition, doubly so when there is no easily observed organic cause for the difference, such as injury to the speech apparatus or deafness. When faced with a non-verbal person with autism, the lack of speech has bothered many people so greatly that the person cannot be seen as human.

We also like to believe that humans are social in ways that animals are not. We hold that there is a standard level of ‘relatedness’ present in all normal humans. Because the behaviour of people with autism, and especially young children with autism, challenges this assumption, our society finds it especially difficult to accept. As demonstrated by the quotation from Bryna Siegal that opened this discussion, metaphors of ferality, monstrosity, inhumanness, zombification or even death are commonplace in narratives of autism, and are particularly tied to the issue of social behaviour. To provide a few further examples, Bettelheim described children with autism as being ‘dehumanised’ (1967: 7) and ‘animal-like’ (1967: 360), while Frances Tustin called them ‘monsters’ (Tustin, 1992: 13).

Our culture currently demands greater degrees of flexibility from people than ever before in human history. Globalisation requires physical, linguistic, and cultural mobility of workers; modern working practices require multi-tasking, lifelong learning, and an affinity for teamwork. Individuals who find it hard to meet these new standards – people like you and me, perhaps, not just people on the autistic spectrum – can find it hard to cope. I would argue, though, that lack of flexibility would not have posed much of a social or personal problem during most of the human past. The definition of it as not just a social and personal problem, but an actual medical problem, is an indicator of a changing definition of what it is to be normatively human.

Monsters, as Tustin’s use of the word to describe children with autism indicates, are beings that trouble the border between human and animal, living and dead. Societies construct their own monsters based on what they fear most, and their concept of normality. In ancient times we feared capricious acts of God, natural disasters, and the machinations of demons and other unseen sources. Because oral speech is one of the most obvious dividing lines between humans and our simian cousins, lack of oral speech has frequently been seen as an especially troubling difference, and culturally specific explanations have been sought and found. As Rosemarie Garland Thomson writes: ‘disability ... is the attribution of corporeal deviance – not so much a property of bodies as a prop-

erty of cultural rules – about what bodies should be or do’ (Thomson, 1997: 6).

It is notable that of the six cases of ‘demonic possession’ discussed in some detail in the New Testament of the Bible, two concerned mute people (Matthew 9:32–34 and Luke 11:14–26; Matthew 12:22–28). The creator of ‘monsters’ in these stories was an outside, unknowable force to be battled through spiritual intervention. Later on, advances in medical knowledge relocated the source of the ‘problem’ to within the mute body, to be controlled and combated through medical technologies.

In the nineteenth and twentieth centuries, mechanisation was a core social fear. It is a fairly short trip from Frankenstein’s monster to Bettelheim’s ‘Joey the Mechanical Boy’ (Bettelheim, 1967: 233–339). Indeed, Bettelheim made these parallels explicit when he stated that ‘[the] typical modern delusion is of being run by an influencing machine’ and that ‘in this sense Joey’s story might also be viewed as a cautionary tale’ (Bettelheim, 1967: 234). So when Bettelheim described Joey as ‘a complex machine’ and a ‘boy-machine’ (1967: 235), ‘a robot’ (1967: 236) and ‘a machine-powered body’ (1967: 261), it was a construction that tapped into culturally specific social anxieties about humanness.

This is not a fear that has disappeared, as a quick look at popular representations of autism demonstrates. The figure of autism is most frequently deployed in science fiction or speculative fiction, a genre that routinely explores notions of humanness and has actually dealt reasonably sensitively with autistic characters. Still, it is interesting that characters with autism in this genre are often used in the way other authors might employ robots, cyborgs, androids or aliens. If, as Keith Piper outlines, ‘the android’s concealed mechanical body makes it a metaphor for the other, able to masquerade as a member of the dominant norm ... [it] can thus be seen as activating metaphorical anxieties about such specters as the infiltrator, the fifth columnist, the “red under the bed,” the closet-dwelling sexual other, the “international Jew,” and the “white nigger”’ (1991: 97), people with autism cut an even more troubling figure in narratives exploring the boundaries of humanness. Unlike the ‘human-like’ android, which can at least be revealed as a manufactured creation, they are ‘inhuman’ only in the sense of being defined as such by dominant notions of normality.

Not all such characters may be intended purely as metaphor, of course. Just as depictions of cyborgs, androids and robots in print and film fictions also address our uneasy relationships with the machines and computerised systems that share our planet, these depictions of autism may at times be explorations of our uneasy relationship with people who have autism or other neurological differences. Elizabeth Moon’s *The Speed of Dark* (2002) is a very worthy example of this possibility.

Old fears continue to find expression in representations of autism, but new ideas about monstrosity are emerging. As we conquer the secrets of the human genome and apply technology to the most basic processes of life, such as creating embryos in the laboratory, our latest monsters are those whose genes seem to threaten the possibility of perfection.

Currently, the majority of funds spent on autism research are attached to genetic studies. There will be no discovery of an 'autism gene', however, although patterns may be discerned, and pre-natal tests for 'risk' developed (Muhle et al., 2004). Already adults with autism are warning that the most likely outcome of genetic testing, as seen in Down's syndrome, will be pressure to terminate pregnancies that might result in autistic children. Because the multiple genes involved are apparently quite common, and because the autistic spectrum is so broad, this process will threaten the lives of the potentially quite functional as well as the severely impaired. The title of a recent mass-media article on the topic – 'Would you have allowed Bill Gates to be born?' (Caplan, 2005) – provides a vivid sketch of how far this process has gone.

The mainstreaming of a catastrophic medical model of autism reaches its apotheosis in discussions of the alleged 'autism epidemic', often dressed up with descriptors such as 'alarming', 'disaster' and 'catastrophe'. To provide just one quotation, Rick Rollens, a California political operative and parent of a son with autism whose advocacy was instrumental in starting the nation's largest autism research centre, said: 'The hordes of autistic children are here. The social and fiscal disaster that is the autism epidemic is upon us. God help us' (Rollens, 2004).

Ever-increasing social atomisation also causes anxiety, with autism deployed as both metaphor and example. In the online journal *Literary Kicks*, Levi Asher (2005) muses that 'autism might be the metaphor for our new millennium, or at least our new millennium's first decade'. In an essay that brings Sontag's writing on AIDS as the metaphor that characterised social anxieties in the 1980s to bear on Mark Haddon's 2003 novel, *The Curious Incident of the Dog in the Night-Time*, Asher writes:

The autistic response is a response many of us have used in certain situations. Block out the intruder. Strangers are dangerous. Touch is bad. Change is scary. Barriers are important. Mysterious forces control us, and only our routines and our rituals keep us safe. (Asher, 2005)

This idea of autism as a metaphor for an increasingly fragmented, disconnected, and dissociative society is interesting, but it is also based on a poor understanding of autism as it is actually experienced. As Asher and those who commented on his *Literary Kicks* piece noted, however, it is a metaphor whose use is increas-

ing: related neologisms include ‘post-autistic economics’ and ‘momentary autism’. It also refers back to Erich Fromm and others who spoke of modern, technological society in terms of ‘schizophrenia’ or ‘autism’ over 30 years ago.

Another commentator, Harvey Blume of MIT, suggests a different reason for popular culture’s recent romance with autism. ‘The media is stuck on autism because of the zeitgeist,’ he wrote. ‘And the zeitgeist, in turn, at least for now, seems never to stray too far from the Internet ... the mental processes of autistics can stand in as symbols of the associative hyper-linking graphic chaos of the World Wide Web’ (Blume, 2004). Blume goes on to consider the possibility that these representations are actually closely related to representations of cyborgs, but with the difference that they suggest human beings are themselves changing to meet new technologies. We aren’t being rewired per se; we are perhaps discovering that some of us are already differently wired, and coming to value that difference – or being frightened or intrigued by these newly revealed differences, as the case may be. Blume’s representation is also reminiscent of clinical psychologist Erich Fromm’s (1973) deployment of autism in his description of the ‘cybernetic man’, alienated and robot-like, of whom he considered the autistic person to be the epitome.

Some might argue that these representations of autism are only fictions, after all, and deserve little serious attention. This kind of dismissal is problematic. As Maria Truchan-Tataryn has argued, fictional portrayals ‘slip out of imaginary discourse to shape the perception and reception of real individuals with disabilities and, in turn, translate into policy which further defines and confines lives and lifestyles’ (Truchan-Tataryn, 2003: 207).

Autism becomes ‘storied’ through its depiction in popular culture, as well as in the pages of medical texts. In an examination of how Hollywood depictions of the Vietnam War produced certain ways of thinking about the war, John Storey points to how discourses that become part of a society’s ‘regime of truth’ may exert power. In the case of these film narratives, a particular discourse migrated from popular culture to political rhetoric and ideology, replacing or guiding the reinterpretation of other discourses (Storey, cited in Grainge, 2003: 99–119). This has certainly happened with the medicalised discourse of autism, and may happen in future with other discourses of autism.

Sometimes the way disability is narrativised in popular culture is part of a deliberate attempt to change the nature of public discourse. Paul Darke (1999) and others have pointed out how film representations of disability in Nazi Germany were employed to change public opinion about murdering people with disabilities. Darke directs the reader’s attention to *Ich Klage An* [I Complain], a 1941 film in which a young disabled woman begs the State to kill her, and

becomes a heroine when she succeeds. He notes that popular culture products **affect?** people with disabilities as well as general audiences. They make a difference in how people feel about themselves, as well as what they believe about and do to others.

Truchan-Tataryn looks at possible links between representations of disability in Canadian literature and 'a eugenic strain' (2003: 209) within it being expressed in relation to the so-called 'mercy killing' of Tracy Latimer, a 12-year-old with cerebral palsy, in 1993. This line of thought can be extended to representations of autism. In 2001, the Autism Society of Canada reported that 50 per cent of the disabled children murdered by their parents in the previous five years were autistic (Simmermon, 2001). If Truchan-Tataryn's analysis is correct, labelling people with autism as unworthy of life may have had some truly horrific effects.

Fundamentally, to conceive of autism as always denoting impairment and deviance means relegating people with autism to a subordinate position: to disable them, whether the condition itself has caused functional impairment or not. As Gleidman and Roth (1980, cited in Fine and Asch, 1988: 12) put it, 'the label of disability carries with it such a powerful imputation of inability to perform any adult social function that there is no other descriptor needed by the public'. Such labelling is a political act, in that it ignores the role of environment, social practice, and social beliefs in the construction of both 'autism' specifically and disability in general. If, as Davis writes, 'the disabled body is not a discrete object, but rather a set of social relations' (1995: 11), the effect of prevailing ideas about autism has generally been to hide the set of social relations that actually defines 'autism' behind a smokescreen of medicalised discourse.

Individuals on the autistic spectrum who are able to recognise the power differentials mobilised by medicalised discourses experience great difficulty in challenging them, even when they are able to launch articulate responses. For those who experience very significant impairment due to ASDs, such as people with learning difficulties and severe communication impairments, being positioned as less than human has been even more dangerous.

Dehumanisation of people with autism, whether it comes through comparisons with robots, disease analogies, or discussions of genetic 'risk', has very real effects on care and treatment decisions. For example, although the use of overt behaviour modification techniques on humans became somewhat taboo following World War II, even theorists who attacked the work of B. F. Skinner seemed unconcerned about the continuing use of such methods on animals and 'subnormal' children, in particular children with autism.

Ivar Lovaas pioneered the use of such methods at the University of California

at Los Angeles (UCLA). His work first came to the attention of the general public through a profusely illustrated article in *Life* magazine entitled 'Screams, Slaps and Love' (Moser and Grant, 1965). It opens with the lines: 'Enraged bellows at the boy, then a sharp slap in the face. This deliberate, calculated harshness is part of an extraordinary new treatment for mentally crippled children' (Moser and Grant, 1965: 90). Lovaas himself is shown administering an electric shock to a nine-year-old girl, 'to give her something to be anxious about' (Moser and Grant, 1965: 93). The language of the article seems extreme, but it simply echoes what had already been said by the biggest names in the field of autism research. 'Billy', on whom the article concentrates, is described as 'uncontrollable', 'diabolically clever', and even as 'a Frankenstein monster' (Moser and Grant, 1965: 96). Against such an implacable, inhuman enemy, what is a slap, or even an electric shock?

The picture changes if dehumanisation is refused. As one organisation opposing these practices has declared:

The use of aversives is a human rights issue and a civil rights issue. When we allow punishments to be used on persons with disabilities which would be illegal if used on persons without disabilities, we are denying them equal protection under the law. Even our other devalued populations – people who are elderly, homeless, or in prison – cannot legally be 'treated' with aversives, nor do we permit animals to be trained or treated by these means. (Autism National Committee, 1999)

The National Institute of Mental Health funded another intriguing study at UCLA in 1971. A severely neglected and deprived 'wild child' known as Genie, who was not autistic but displayed similar impairments due to her experiences, was studied by researchers curious about whether Skinner or Chomsky had been right in the debate on human language (Rymer, 1993). Lovaas's lab was close by on the same university campus, and he had a well-known interest in children like Genie. Many years later, a lecturer researching the Genie case enquired as to why Lovaas had not been brought in to assist with the study. She was told by UCLA linguist Susan Curtiss, who had been a member of the original research team, that 'the team felt that Dr. Lovaas' approaches were not well suited to Genie who required nurturance, affection, love, and an opportunity to experience the world' (Gadbois, 2001). It was apparently a given that such niceties were not required by children with autism.

Lovaas's research group no longer condones the use of pain-based aversives, instead concentrating on the use or denial of positive reinforcement for desired behaviour. Unfortunately for people with autism and related conditions, aversives have not gone out of style in some places, and denial of positive reinforcements can also have tragic consequences. For example, in 1995

the Massachusetts Department of Mental Retardation forced an overhaul of procedures after a 19-year-old girl with learning difficulties apparently starved to death when the 'positive reinforcer' of food was denied her by personnel at a residential care centre (Autism National Committee, 1995).

Despite parent enthusiasm for his methods, Lovaas has said and written some quite troubling things over the years. On several occasions he has equated humanness with normality, as in the following quotation from a 1974 article in the popular psychology magazine *Psychology Today*: 'You have a person in the physical sense – they have hair, a nose and a mouth – but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build the person' (Chance, 1974: 76).

Acceptance of dehumanising representations of autism may have had other, deadly consequences. 'Mercy killings' of people with autism by their caregivers are, sadly, more common than one would like to think (Palermo, 2003). Such crimes are almost never punished, because the victims are represented in ways that devalue them as human beings but make it easy to pity and sympathise with their carers (see McKim, 2002, for a recent example of this phenomenon). Typically, the social context of inappropriate or non-existent support for people with autism and their families is not addressed as part of the response. Two websites (Smith, 2005, and Seidel, 2006) were available at the time of this writing that list such murders, with information about the almost uniformly light sentences (if any) given to the perpetrators.

Creating fears of 'hordes' of diseased burdens on the state allows, perhaps even demands, the use of heroic measures to combat the menace. Yet when Catherine Maurice (2000) makes the argument: 'Yes, aiming for and achieving recovery from autism is expensive. So is chemotherapy. So is a lifetime of state-supported custodial care. Why would we not attempt to recover anyone from cancer, or autism?' the discussion is not pursued. When autism is equated with life-threatening diseases or devastating natural disasters, the response is sadly predictable.

In summary, the identification of autism with self-loss, otherness and dehumanisation pervades the dominant, medicalised discourse of autism. These descriptors say little about the nature of autism, and expose people so diagnosed to a higher risk of degrading and potentially dangerous treatment. They also pose a risk to all of us, because these representations of people with autism have been entwined from their very beginning with an effort to define what it is to be normatively human, and act to constrain the boundaries of acceptable human variation.

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